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The Role of Palliative Care at the End of Life

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ABSTRACT

The goal of palliative care is to relieve the suffering of patients and their families by the comprehensive assessment and treatment of physical, psychosocial, and spiritual symptoms experienced by patients. As death approaches, a patient's symptoms may require more aggressive palliation. As comfort measures intensify, so should the support provided to the dying patient's family. After the patient's death, palliative care focuses primarily on bereavement and support of the family.

INTRODUCTION

While dying is a normal part of life, death is often treated as an illness. As a consequence, many people die in hospitals, alone and in pain.[1] Palliative care focuses primarily on anticipating, preventing, diagnosing, and treating symptoms experienced by patients with a serious or life-threatening illness and helping patients and their families make medically important decisions. The ultimate goal of palliative care is to improve quality of life for both the patient and the family, regardless of diagnosis. Although palliative care, unlike hospice care, does not depend on prognosis, as the end of life approaches, the role of palliative care intensifies and focuses on aggressive symptom management and psychosocial support.

Helping patients and their families understand the nature of illness and prognosis is a crucial aspect of palliative care near the end of life. Additionally, palliative care specialists help patients and their families to determine appropriate medical care and to align the patient's care goals with those of the healthcare team. Finally, establishing the need for a medical proxy, advance directives, and resuscitation status is an integral part of palliative care at the end of life.

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MODELS OF CARE

The traditional medical treatment model has become dichotomous, leading physicians to provide curative or aggressive treatment initially and to initiate comfort care only when other measures have failed. Palliative medicine establishes goals to relieve suffering in all stages of disease and is not limited to comfort care or end-of-life care (Figure[2]).[3]

The terms palliative care and hospice care are sometimes used interchangeably. According to the National Quality Forum, hospice care is a service delivery system that provides palliative care/medicine when life expectancy is 6 months or less and when curative or life-prolonging therapy is no longer indicated.[4] Therefore, it is important to distinguish that although hospice provides palliative care, palliative care is not hospice. Not all available therapeutic palliative care modalities are provided within the hospice service delivery system.

THE CONCEPT OF TOTAL PAIN

The alleviation of suffering is an essential goal of medical care. To treat it, however, providers must first recognize pain and suffering.[5] Saunders first described the concept of total pain (Table 1)[6] and interaction among the various sources of pain and suffering.[7] Total pain is the sum of the patient's physical, psychological, social, and spiritual pain. This concept is central to the assessment and diagnosis of pain and suffering.

Because psychological distress, lack of social support, and physical pain are associated,[8] treating a patient's total pain is imperative, especially at the end of life. Optimal pain relief will not be possible unless all the elements of total pain are addressed. Clinicians should utilize other members of the multidisciplinary team, such as social workers and chaplains, to better treat suffering related to the different domains of total pain.

Figure. Models of healthcare delivery. (Reproduced with permission from the National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care. 2008.)[2]

MANAGING COMMON PHYSICAL SYMPTOMS

Patients near the end of life may experience extreme symptoms that include physical, spiritual, and psychosocial suffering. Preventing and managing these symptoms while optimizing the quality of life throughout the dying process is the goal of palliative medicine.[9] Factors important to seriously ill patients include adequately controlling pain and other symptoms, avoiding prolongation of the dying process, achieving a sense of self-control, finding meaning in life, and relieving the care burdens of family and loved ones while strengthening and completing those same relationships.[10] As death becomes nearer, the symptom burden increases while the patient and family tolerance of physical and emotional stress decreases. At this time, primary palliative care interventions should take precedence, and the focus on restorative care should decrease. The triggers for the shift to palliative care include the following four symptoms.

Physical Pain

Pain is one of the most prevalent symptoms near the end of life. Unrelieved pain can be a source of great distress for patients and families and exacerbate other symptoms. Therefore, the adequate management of pain at the end of life is imperative. Although opioid analgesics are the standard of care for treating moderate to severe pain in patients with advanced illness, the false fear that opioids induce respiratory depression and hasten death is a major barrier to their use at the end of life. However, both effects are uncommon when opioids are given at appropriate doses. Clinicians who care for the chronically ill and for those at the end of life should acquire competency in pain management.[11]

Dyspnea

Dyspnea, the subjective sensation of breathlessness, is a frequent and distressing symptom, particularly in dying patients. Opioids and benzodiazepines are the most widely prescribed medications for treating dyspnea. As death approaches, a clinician may use continuous infusions to manage symptoms and relieve suffering if scheduled or as-needed doses are not adequate. The clinician should continually assess the patient and make adjustments that will control symptoms.[12]

Table 1. Four Components of Total Pain

P	**Physical** problems, often multiple, must be specifically diagnosed and treated.
A	**Anxiety**, anger, and depression are critical components of pain that must be addressed by the physician in cooperation with other healthcare professionals.
I	**Interpersonal** problems, including loneliness, financial stress, and family tensions, are often interwoven into the fabric of a patient's symptoms.
N	**Not accepting** approaching death, a sense of hopelessness, and a desperate search for meaning can cause severe suffering that is unrelieved by medications.

Reproduced with permission from Bial A, Levine S. The assessment and treatment of physical pain associated with life-limiting illness. *Hospice/Palliative Care Training for Physicians: UNIPAC*. Vol 3. 3rd ed. Glenview, IL: American Academy of Hospice and Palliative Medicine; 2007.[6]

Restlessness

Providers should recognize the signs and symptoms of the restlessness associated with delirium at the end of life (Table 2).[13] The most common identifiable cause of delirium in the hospital setting is medication: anticholinergics, sedative-hypnotics (eg, benzodiazepines), and opioids. Delirium and restlessness at the end of life are usually characterized by anguish (spiritual, emotional, or physical), anxiety, agitation, and cognitive failure. The treatment of terminal delirium usually requires the use of a major tranquilizer such as haloperidol.[14]

Death Rattle

As responsiveness decreases toward the end of life, it becomes increasingly difficult for patients to control oropharyngeal secretions. The death rattle of the actively dying is the sound of air movement across pooled secretions. Although not a cause of suffering for the dying, the death rattle can be disturbing for loved ones to hear. Repositioning the patient's head and using anticholinergics such as atropine or scopolamine are the mainstays of treatment.[15]

PSYCHOSOCIAL, SPIRITUAL, AND BEREAVEMENT SUPPORT

Once the physical adverse symptoms and distress have been successfully addressed, it is important to

Table 2. Signs of End-of-Life Restlessness

The constellation of end-of-life restlessness symptoms may include the following:

- Skin mottling and cool extremities
- Mouth breathing with hyperextended neck
- Respiratory pattern changes such as Cheyne-Stokes
- Calling out for dead family members or friends
- Talking about packing bags, taking a trip, going for a car ride (any reference to preparing for a trip)
- Periods of deepening somnolence

Reproduced with permission from Policzer JS, Sobel J. Management of selected nonpain symptoms of life-limiting illness. *Hospice/Palliative Care Training for Physicians: UNIPAC*. Vol 4. 3rd ed. Glenview, IL: American Academy of Hospice and Palliative Medicine; 2007.[13]

broaden the integrated response of the interdisciplinary treatment team to address the psychosocial and spiritual issues that are an inherent part of the dying process. A comprehensive psychosocial and spiritual assessment allows the team to lay a foundation for healthy patient and family adjustment, coping, and support. Skilled expert therapeutic communication through facilitated discussions is beneficial to maintaining and enhancing relationships, finding meaning in the dying process, and achieving a sense of control while confronting and preparing for death (Table 3).[16]

Compassionate palliative care requires a professional readiness of those specialized in this field to explore the integrity-preserving issues that will foster growth in dignity and transcendence. Reflective open-ended questions are key in optimizing this communication and assessing the willingness of the patient and caregivers to engage. Physicians, psychologists, nurses, social workers, and chaplains can assimilate and negotiate the interpersonal relationship skills and intimacy required to enhance the patient's peace and psychosocial spiritual comfort (Table 4).[16]

THE ''WORK'' OF DYING

Many patients imagine that death comes suddenly, but for many, the knowledge that one's death is imminent comes first. Those with this awareness often must complete certain tasks to allow a peaceful death such as offering forgiveness, being forgiven, acknowledging regrets, finding closure in professional and community relationships, and saying goodbye to family and friends.

Table 3. Psychosocial and Spiritual Assessment of the Patient With a Life-Threatening Illness: Sample Screening Questions

Psychosocial Assessment Domain	Screening Questions
Meaning of illness	*''How have you made sense of why this is happening to you?''*
	''What do you think is ahead?''
Coping style	*''How have you coped with hard times in the past? What have been the major challenges you have confronted in your life?''*
Social support network	*''Who are the important people in your life now? On whom do you depend and in whom do you confide about your illness?''*
	''How are the important people in your life coping with your illness?''
Stressors	*''What are the biggest stressors you are dealing with now?''*
	''Do you have concerns about pain or other kinds of physical suffering? About your and your family's emotional coping?''
Spiritual resources	*''What role does faith or spirituality play in your life? What role has it taken in facing difficult times in the past? Now?''*
Psychiatric vulnerabilities	*''Have you experienced periods of significant depression, anxiety, drug or alcohol abuse, or other difficulties in coping?''*
	''What kinds of treatment have you had and which have you found helpful?''
Economic circumstances	*''How much of a concern are financial issues for you?''*
Patient-physician relationship	*''How do you want me, as your physician, to help you in this situation? How can we best work together?''*

Reproduced with permission from Block SD. *JAMA.* 2001 Jun 13;285(22):2898-2905.[16]

Table 4. Useful Questions for Clinicians

A. Mobilizing a patient's coping strengths and inner resources

- *''What will help you feel that you have lived up to your own ideals in the way you've dealt with your illness/your death?''*
- *''What could you do that would help you feel that this has been a meaningful time for you and the people you care about?''*
- *''How do you want to be remembered by the people you care about?''*
- *''What are some of the ways you have found yourself growing or changing, or hoped that you could grow or change in this last phase of your life?''*
- *''What are some of the moments when you've felt most discouraged and downhearted as you've faced your illness?''*
- *''What are the biggest barriers you find to feeling secure and in reasonable control as you go through this experience with your illness?''*
- *''What are the resources and strengths within you that can help you cope?''*

B. Eliciting a patient's goals for healing and strengthening relationships

- *''Are there important relationships in your life, including relationships from the past, that need healing or strengthening?''*
- *''Are there relationships in which you feel something important has been left unsaid?''*
- *''Do the important people in your life know what they mean to you?''*
- *''Are there stories, values, or ideas that you want to transmit to people as part of your legacy?''*
- *''Are there ways that you can help your family now to prepare for and deal with your death?''*
- *''How might you be able to continue to be a presence in the lives of people you love after you are gone?''*
- *''How would you like to say goodbye to the people who have been important to you?''*

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GUIDELINES

The National Cancer Comprehensive Network (NCCN) has published guidelines for the palliative care of cancer patients.[17] Recommendations offered by NCCN cover many of the topics discussed in this article and are an excellent resource for the palliative care of patients with cancer and other life-threatening conditions.

CONCLUSION

The role of palliative care at the end of life is to relieve the suffering of patients and their families by the comprehensive assessment and treatment of physical, psychosocial, and spiritual symptoms patients experience. As death approaches, the symptom burden of a patient may worsen and require more aggressive palliation. As comfort measures intensify, so does the support provided to a dying patient's family. Once death has occurred, the role of palliative care focuses primarily on the support of the patient's family and bereavement.

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